Testimony of James A. Bunker

To the SUBCOMMITTEE ON NATIONAL SECURITY, EMERGING THREATS, AND INTERNATIONAL RELATIONS, Christopher Shays, Connecticut Chairman

June 1, 2004

Dear Committee Chair and members of the committee, on behalf of the Veterans Information Network (a grass roots organization of Kansas and Missouri Veterans) and myself, I would like to thank you for giving me time to address you about the issues of Gulf War illness and research problems.

First, let met take a moment to briefly provide background about my involvement and interest in Persian Gulf Illness.

I deployed to the Gulf War with the Fourth Battalion – Fifth Field Artillery Regiment as a First Lieutenant, stationed at Fort Riley Kansas. While in the war zone, the Big Red One blew up a large Iraqi ammunition storage area. At the time of this demolition, I became ill. I was treated for all of the classic symptoms of nerve agent poisoning, including convulsions. Then, I was given the antidote for the nerve agent and medically evacuated. Over time I completely lost the use of my arms and hands. I have recovered some use in them, although some numbness, weakness, and tingling continues. The problems I have with my legs have subsequently been identified as a problem with my sciatic nerve and often require the use of crutches. Although I have had an abnormal EEG, it is not considered to be seizure activity. Additionally, I deal with headaches and cognitive dysfunction during the day. All of these greatly limit my activities and contribute to my desire to ensure that this issue is addressed and a cure is found.

Returning home, I saw other troops getting sick and being forced out of the service, much the same way I was. No one seemed to care what was making us sick; they only wanted us out to meet a draw down level. On 19 June 1992, I was discharged from the army. For a career soldier, a medical discharge is not an easy way to lose one's life long dream, and with no hope of a job due to my illness, life was going to get even harder. At that time, I still could not use my arms and I was barely able to walk without the use of crutches. The army told me the VA would help me; the VA said it was all in my head

Within a short time, I received my service-connected disability rating from the VA. I began contacting and working with other veterans to find out what happened to us. The first person I talked to was Vic Sylvester, out of Texas who introduced me to online groups whose mission was to find other veterans, uncover common illnesses, and relay information concerning doctors we could go to and any treatments that might help.

As a grass root group, we all worked to pass the first Gulf War Health Bill in November of 1994. At the time I worked with the other groups on the first self-help guide for gulf war veterans. When they were completed, I bought over 300 of the self-help guides to give out in the state of Kansas. This resulted in many fellow gulf war veterans calling me to get understanding about their illnesses and advice with their VA claim for benefits. My involvement gradually led me to my becoming the point of contact for media outlets

In February of 2001, I put together the 'Project Honor' a daylong tribute held at the Kansas Capital honoring all those that have served. We ended the day with the reading of the names of

those who served and died in the Gulf War theatre. Following this we played taps and gave a 21-gun salute.

I formed a group called Veterans Information Network to help get several things passed in Kansas to help our fellow veterans. The most important piece of legislation we worked on was the creation of the Kansas Persian Gulf War Health Initiative which created the advisory board and study of Kansas veterans which then produced a significant piece of research into Gulf War Illness. The study was done by Dr. Lea Steele and is best known as 'The Kansas Study.'

The Kansas study was the first to identify clear links between Gulf veterans' health problems and the time and places in which they served. Results suggest that the unexplained health problems may be due to multiple factors. The study, conducted by telephone interview, compared the health of Kansas Gulf War Theatre veterans to non theatre veterans who served during the same period. A scientific article describing the study results was published in the November 15, 2000, issue of The American Journal of Epidemiology.

The study found B types of symptoms connected with Gulf War service: neurological symptoms, pain symptoms, gastrointestinal problems, respiratory problems, problems associated with fatigue and sleep difficulties, and skin problems.

About a third of Gulf veterans affected overall, 34% of Kansas veterans who served in Desert Shield or Desert Storm had symptoms of Gulf War illness. The severity of these problems varied widely. Some veterans had relatively mild symptoms; others were so ill they could no longer work.

The study also found that veterans who did not serve in the Persian Gulf, but reported getting shots from the military during the war, may have some of the same health problems as Gulf War veterans. Gulf War illness symptoms were found in 12% of non-Gulf veterans who said they got vaccines during the war, compared to less than 4% of veterans who did not get vaccines.

The study is significant because it showed that a state could use 1/10 of 1% of the money that the VA spent on GWI and come up with answers that the VA or DOD never did regarding the true status of the health of Veterans within the state. This study made Kansas the leader when it came to Gulf War Illness research.

The findings in this study also showed that there are several issues that still need to be addressed with regard to the care and health of the troops. While the 1994 legislation covering undiagnosed illnesses facing Gulf War Veterans was significant and ground breaking at the time, the legislation is incomplete.

The reason I say that it is incomplete is because it does not address the illnesses that are diagnosed in veterans of the Gulf War at a statistically higher rate than in other veterans or controls.

The following are my recommendations based on the work done in Kansas:

1. Get the illnesses that are being diagnosed at a higher rate in gulf war veterans presumptive service connected for them.

This is needed now because many of the veterans are having clams denied for many of these illnesses, even though research has shown a higher rate in PGW veterans. We need your help to change PL103-446.

The Secretary of Veterans Affair, two years ago, added ALS as presumption of service-connection for gulf war veterans. He did this with the rate of ALS being at 2 times the rate of non-gulf war veterans. As you will see below, there are some illnesses here that are being seen in Gulf War Veterans either at the same rate or an even higher rate than the ALS.

The Secretary of Veterans Affair can add them himself and that is one route we could take, but in this time of budget concerns, I feel that legislation is going to be the only effective method to address this in a meaningful way.

With most everyone looking at what is causing Gulf War Illness, it seems that they are over looking the high rates of illness that veterans are diagnosed with.

Table 3 of the 'Kansas Study' that was printed in American Journal of Epidemiology (vol.152.no10, Nov. 2000) shows some of the illnesses and the rates they occur in gulf war veterans over non-gulf war vets.

The illnesses that we need to get presumption of service-connection for are:

	PGW*		Non-		
Condition(s)	(n=1)	,545)	(n = 435)		OR*,t
	No.	%t	No.	%t	_
Skin condition(s) (other than	299	21	26	6	3.83
skin cancer)					
Stomach or intestinal	219	15	32	8	2.13
condition(s)					
Depression	179	12	30	7	1.85
Arthritis	161	11	24	6	1.99
Migraine headaches	160	11	21	5	2.25
High cholesterol	155	11	36	9	1.24
Chronic fatigue syndrome	142	9	5	1	8.70
Bronchitis	138	10	19	5	2.61
High blood pressure	134	9	33	8	1.24
Allergies	119	10	23	7	1.41
Posttraumatic stress disorder	98	6	6	1	4.74
Asthma	63	4	9	2	2.08
Alcohol or drug dependence	43	3	8	2	1.47
Heart disease	37	2	7	2	1.56
Lung disease	37	2	2	< 0.5	4.77
Thyroid condition	30	2	4	1	2.32
Fibromyalgia	24	2	2	< 0.5	3.69
Skin cancer	23	2	7	2	1.17
Diabetes	21	1	5	1	1.22
Cancer (other than skin	18	1	4	1	1.21

cancer)					
Seizures	15	1	1	< 0.5	4.17

As one can see, skin conditions is very high at 3.83 time the rate of non-deployed veterans, and the reliability of this study is high too; but there needs to be more work done to show the types of conditions that one is seeing nation wide, not just in Kansas.

Some of the illness, like bronchitis, asthma, and lung disease, are closely related and can lead to less productive lives for the veterans due to their service. VA compensations is given to sick veterans for their loss of earning power. With so many illnesses continuing to show up in the veterans we need to work at getting the VA to compensate them.

Look closely at the full study provided to you by Dr. Steele. In the full study you will see we do not only need to get these illnesses on a list for presumptive service connection; but we also need to do more research into this area to positively identify nation wide trends in the illnesses of Gulf War Veterans.

2. Track known disease groupings within the veterans' populations in correlation with civilian entities to include death rates.

One example of this would be Multiple Sclerosis. Because many of the recognized illnesses found in civilian populations have a higher incidence within the veterans' populations, DoD and the VA should be working with the civilian entities that work with persons who receive civilian diagnosis of these conditions due to the fact that many veterans do not use the VA system for their health care.

At the current time, the only health tracking being done is related to those who do use the VA for their health care, leaving many veterans uncounted.

There are veterans who are aware of statistically higher incidents of degenerative neurological issues within the Gulf War Veterans community. These veterans feel the true numbers of veterans with these problems is underrepresented in the current illness counts due specifically to the fact that because many veterans are not service connected and do not use the VA for care, their numbers are not included in the illness reporting system as it stands now. One such veteran is Julie Mock who can be reached at jmock@ngwrc.org

One way to ensure that all affected veterans are counted would be to correlate social security numbers of veterans with applications for social security disability applications, as well as social security records on deaths.

Another way would be to make a concerted effort to contact organizations such as National Multiple Sclerosis Society, or American Heart Association to make sure that veterans who request help from these agencies or who apply for national registries are counted separately from their civilian counterparts in an effort to truly determine who is ill, and with what.

3. There needs to be a closer look at the birth defects in children of veterans more so at the female veterans.

Studies conducted both inside and outside the VA and DOD have shown a higher number of birth defects in children born to the veterans of the gulf war. Further research should be conducted into the types and severity of these defects, with attention given to the incidence of neurological, behavioral, and learning deficits as well as just the physical abnormalities. I am sure that Betty Mekdeci, executive director of the Association for Birth Defects Children will cover this area more thoroughly than I am. She came to the last National Gulf War Conference to talk about the birth defects.

4. Work to get all the data on the other NBC sites we blew up out and a new death rate table done using these sites too.

Being one that became sick right after we blew up an ammo stock- pile, I feel it is very important that the DoD openly show all the sites that we blew up that contributed in any way to the chemical gas and fallout that troops in the theater of operations were exposed to. I have personally seen photos by Paul Lyons, president of Desert Storm Justice Foundation, Inc. that showed the 1st AD in an area filled with chemical munitions, yet the information about the demolition of those munitions remains classified, and is not part of the modeling done regarding potential exposure levels in theater.

The problem with this withholding or denial of exposure is that the troops cannot receive appropriate medical care for the long-term symptomology of this kind of exposure if they do not know they were exposed. Further, without the other chemical munitions demolitions being addressed, we have no clear picture or accurate data concerning the true rates of illnesses and deaths due to this kind of exposure, and we continue to perpetrate the same kind of injustice we have seen in the past.

I do believe that it is the job of the VA and DOD to work at finding out what is wrong and what will make the veterans better in an honest and systematic way; but repeatedly we have seen that it not the case. We have seen that with the veterans of WWII and the A-bomb tests. We have seen it with the Viet Nam vets and Agent Orange. Only now are we learning about how our troops have been used as guinea pigs with things like Project SHAD.

In all of these, our federal government should have acted to help the veterans, but, for whatever reason, it did not. It takes projects like what we have done in the great State of Kansas to bring changes that will help our veterans.

5. Separate research funding from the entity responsible for providing care and compensation funds to the Veterans.

It seems as though it takes having an independent entity to allot research funding based on the merits and potential findings of that research to handle the money before meaningful results and studies will be conducted such as the Kansas study and other independent research that has shown significantly different results than that of the VA and DoD studies.

These independent studies have shown that we need to take the research funding away from the VA and let state or private researchers do the work. One entity that could potentially work as the entity responsible for funding independent research is the RAC.

Because the RAC is in a unique position to hear about new and innovative studies from the researchers both within the DoD and VA system as well as from the civilian sector. The RAC has the potential ability to guide exploration into previously unaddressed areas of research into the illnesses of the Gulf War Veterans, while having a historical perspective of what research has already been done. I suggest this in the hope that we would not continue to fund redundant studies, or studies simply designed to refute what has already been shown to be accurate.

Essentially, the RAC would still work as it is now, but with the added power of being able to direct the spending the VA's gulf war research money. Further, they would be overseeing the studies and would have access to the interim data, and have the power to withdraw funding or terminate the studies if the study is not following the protocol written in the proposal.

By taking control of the research and funding for research away from the VA, one will reduce conflict of interest that is inherent in the current situation. This conflict is clearly due to the need for the VA to both save money and limit costs to the government due to veterans claims for compensation and health care; while simultaneously being responsible for finding out if health problems exist due to service to this nation, and if the VA should compensate for them.

While in the service, we are trained that the mission comes first. We were also trained to take care of our men to make sure the mission was done. That is why even now the DoD will be giving troops pretreatments, to help them if they are exposed to NBC agents on the battlefield. There are some that will point to a 1999 study by the RAND Corporation and a 2000 report from a panel of experts convened by the Institute of Medicine, both of which concluded PB, could not be ruled out as causing Gulf War Syndrome. This set of symptoms includes fatigue, cognitive problems, muscle pain and weakness, and sleep disturbances experienced by some Gulf War vets who served in Iraq in 1990-1991.

Now that we are no longer in the service, the mission of the government is to make sure that veterans have the best treatment for anything that happens to them while serving our country. This treatment should not be denied or held up simply because of cost, or research that has not been done due to conflicts of interest.

6. Base future research on a model similar to the following in the hope of not only finding out what caused the veterans to be ill, but with concern for making the lives of the veterans better.

This is the model for phase two of the Kansas study. The three major research components for this type of study is:

- 1. Evaluating Practical and Objective Clinical Markers for Illness Detection and Classification
- 2. Determining Veterans Progress Over Time
- 3. Identifying Treatments & Activities Associated with Improved Health

These components are summarized below:

1. Evaluating Practical and Objective Clinical Markers for Illness Detection and Classification.

Background: There are currently no well-accepted, objective or practical tests available to diagnose and classify Gulf War Illness. Since this illness appears to actually be a family of syndromes, evaluating the value of a particular test depends upon properly classifying individuals when evaluating specific tests. Based upon the current Kansas database, it is possible to identify individuals with different constellations of symptoms, who would be expected to react differently to different tests.

Methodology: This study will assess whether biological, biochemical, and physiologic measures previously suggested to be associated with Gulf War illnesses are useful in distinguishing between groupings ill veterans and ill from healthy veterans. It will involve small multiple trials which utilize sub-sets of the existing database, initially drawing upon those Veterans most clearly falling into specific categories. It will emphasize only those measures that either use existing technology or technology that could be made readily available in a non-research clinical setting.

Potential Benefits: Veterans who are suffering will stand an improved chance of being correctly diagnosed, receive assistance and potentially receive appropriate treatment when it is available. Identified markers will allow both clinicians and researcher to better understand the nature of Gulf War illnesses, and guide them in developing and providing effective treatments. Objective biological markers lift the burden from those suffering Veterans who are still fighting the battle with those skeptics who do not recognize their suffering.

2. Determining Veterans Progress over Time

Background: Building on the foundation laid in earlier and current research, the Kansas Gulf War Veterans Project is in a unique position to find answers to outstanding questions about Gulf War-related conditions. This is possible both because of the large number of Kansas Gulf veterans for whom baseline data already exist and because of the reputation of the Kansas program for conducting credible research in an even-handed manner.

Data collected since 1998 by the Kansas Commission on Veterans Affairs on over 2,000 Kansas Veterans provided a unique snapshot of their health. It does not show progress over time. Since this data has already revealed that there are sub-sets of illness within this group, following these Veterans over time could provide valuable insight into the course of illness for these sub-groups. It may help identify whether specific findings are associated with Veterans health improving, declining or remaining stable. Additional data, not determined in the 1998 study could also be obtained.

Methodology: This study will utilize the entire database from the 1998 study. Data gathering will be similar to that utilized for the initial research, but further research questions will be added. Morality data on study participants will also be collected through appropriate means. It will continue to utilize sophisticated epidemiological analysis to identify associations and trends. If warranted by results from Research Component # 1(regarding markers and tests), it will attempt to correlate objective findings with prognosis. By identifying who gets better and who gets worse, it will serve as a basis for Research Component #3 (Identifying treatment that works).

Potential Benefits: Determining for Veterans, their families and the Government what to expect over time

Discovering whether certain groups of Veterans are getting better or worse as a guide to treatment and further research. Providing a background rate for potential spontaneous recovery to help identify when treatment has actually aided recovery

Maintaining an invaluable research resource, the Kansas database, that will be a foundation for future research benefiting Veterans

3. Identifying Treatments & Activities Associated with Improved Health

Background: Although both the Institute of Medicine and the Department of Veterans Affairs have attempted to issue treatment guidelines for Gulf War Syndrome, these have proved of minimum value clinically. Rather then being based upon treatments that have been demonstrated to work in this group of Veterans, these instead are a compendium of treatments for diseases that have some similarity of appearance but have not been subjected to testing in this group. Anecdotally, there are sporadic reports of treatment attempts that are claimed to be effective in small groups of Veterans, but these have proven elusive to replicate in other groups of Veterans. Historically, it is worth noting that in other "mystery diseases" (such as Legionnaire's' Disease) the important breakthrough occurred not in an expensive laboratory, but in the hands of a single clinician who tried something that turned out to work.

Currently, there is no established methodology or registry that could provide a clue as to whether a specific treatment, rendered outside the bounds of a clinical trial, might be of value. Furthermore, without a scheme for classifying the subset that a Veteran falls into, treatments that might work for one particular group would appear ineffective if tried on the entire population of sick Veterans.

Methodology: The first phase of this research would be a component of Research Component #2 (Determining Progress over Time), correlating any changes in Veterans health status with both subgroup and any form of treatment. Intensive analysis and follow-up information gathering will be required regarding any treatment purported to work. This will not constitute a clinical trial in any form, but may provide information regarding potential therapies that could later undergo clinical trials.

Potential Benefits: May identify potentially worthwhile treatment options that would otherwise have not been noticed.

Provide a basis for future treatment trials.

Make information about potential treatment efficacy available to Veterans, their physicians and researchers.

Background on the Kansas Persian Gulf War Health Advisory Board

The Kansas Persian Gulf War Health Advisory Board is an unpaid advisory group, appointed by the State of Kansas to provide recommendations regarding research, services and outreach to the Kansas Commission on Veterans Affairs. The nature of the research outlined here is complex, combining medical, epidemiological and laboratory research. It exceeds the capabilities of a single individual, department or institution to accomplish alone. Fortunately, within the State of Kansas there exist individuals who have cooperated and have made themselves available

accomplish these goals. It is foreseen that, with the guidance of Kansas Persian Gulf War Health Advisory Board, this project can be accomplished as a joint venture involving multiple individuals and institutions.

This research project shall rely upon the full cooperation and coordination with the Kansas Commission on Veterans Affairs. However, no portion of the research funding shall be used to support any activities of that organization, except for the direct costs of participation in research. The time frame for this overall project is estimated to be 3 years from the onset of funding availability and appropriate institutional agreements. Work products of some individual components may become available earlier. Because of the potential clinical value of the findings and the benefit to Veterans, findings should be widely disseminated through peer-review journals and other available means.

The following individuals have indicated their willingness to provide their support and cooperation in this project:

Lea Steele, PhD is an epidemiologist formerly employed by the Kansas Commission on Veterans Affairs. She is now a Senior Health Researcher with Kansas Health Institute in Topeka. Dr. Steele also serves as a member of the Veterans Administration Research Advisory Committee.

Beginning in 1997 Dr. Steele directed and conducted the research on Kansas Veterans, funded by the State without outside support, that conclusively demonstrated that;

Many Kansas Persian Gulf Veterans are sick

Their symptoms could be logically grouped into several syndromes

These groupings could be associated with geographical location and time of service as well as exposure to suspected risk factors (such as military immunization programs).

This research was published November 15, 2000 in the American Journal of Epidemiology {152(10):992-1002}. This frequently cited research has spurred other research across the country. Dr. Steele is now a co-investigator in ongoing research at the Midwest Research Institute of Kansas City, Missouri looking at certain patterns and biologic markers in these Veterans. Other states are also interested in studying conducting similar studies of their own Veteran populations.

Frederick W. Oehme DVM, PhD is a research scientist at Kansas State University in Manhattan, where he chairs the Department of Toxicology and the Comparative Toxicology Laboratories at the College of Veterinary Medicine. Dr. Oehme is a member of the Kansas Persian Gulf War Health Advisory Board.

Beginning in 1994 Dr. Oehme directed and conducted research into the toxic synergism between Pyridostigmine Bromide (the nerve gas pill) and common insect repellents or insecticides used by our troops. This research, in an animal model, clearly demonstrated those toxic effects. His findings were published in 1996 in both the Fundamentals of Applied Toxicology {1996 Dec;34(2):201-22} and the Journal of Toxicology and Environmental Health. {1996 May;48(1):35-56}.

Irving A. Cohen, MD, MPH is a physician formerly with the Veterans Administration Medical Center in Topeka. He is currently retired and is assisting this effort as a volunteer. Dr. Cohen is a member of the Kansas Persian Gulf War Health Advisory Board.

Beginning in 1993, Dr. Cohen noticed that Persian Gulf Veterans were suffering physical and psychiatric symptoms unlike those suffered by Veterans of earlier conflicts. He discovered that they had been exposed to pyridostigmine bromide as well as simultaneously exposed to myriad other factors, including pesticides, immunizations, and suspected low-level nerve gas, all of which could combine to disrupt the regulation of acetylcholine, an important neurotransmitter within the human nervous system. He noted that syndromes of acetylcholine disruption were previously documented in separate exposures to low-level nerve gas as well as chronic insecticides.

Genetic differences in the regulation of acetylcholine among individuals also had been documented in the medical literature. His warning and call for further evaluation in 1994 at the National Institute of Health Technology Assessment Workshop on Persian Gulf, is documented in the May 25,1994 Journal of the American Medical Association {271(20):1559-1561}.

Charles T. Hinshaw, Jr., MD is a physician formerly in practice as a pathologist and specialist in Environmental Medicine in Wichita. He is currently retired and is assisting this effort as a volunteer.

Because of his experience treating patients with Multiple Chemical Sensitivity, he was sought out in 1994 by Veterans who noticed similarities between that syndrome and the symptoms some of them suffered from. In 1995, he proposed research into environmental medicine factors effecting exposed Veterans.

Conclusion:

While in the service, I was trained that the mission came first. I was also trained to take care of our men to make sure the mission was done.

Now that I and many like me are no longer in the service, and knowing that we were injured by our service, my personal mission is to ensure as many veterans as possible receive just and proper care and compensation for their injuries and illnesses. The mission of our government should the veteran and making sure they have the best treatment for anything that happened to them while answering the call of our country. The mission we have can be best accomplished by:

- 1. Getting the illnesses that are being diagnosed at a higher rate in gulf war veterans presumptive service connected for them.
- 2 Track known disease groupings within the veterans' populations in correlation with civilian entities to include death rates.
- 3. Taking a closer look at the birth defects in children of veterans more so at the female veterans.
- 4. Work to get all the data on the other NBC sites we blew up out and a new death rate table done using these sites too.

5.	. Separate	research	funding	from the	e entity	responsib	ole for	providing	care and	compen	sation
fu	ands to the	e Veteran	S.								

6. Base future research on a model similar to phase two of the Kansas Study in the hope of not
only finding out what caused the veterans to be ill, but with concern for making the lives of the
veterans better.

Thank you,

James A. Bunker